



# **National Disability Employment Strategy**

## **MJD Foundation Submission to Department of Social Services on the National Disability Employment Strategy**

**May 2021**

### **Table of Contents**

Submission Purpose .....	2
About the MJD Foundation .....	2
Employing Aboriginal people with disability .....	2
Employing people with degenerative neurological conditions.....	3
Questions for consideration .....	4
Recommendations.....	5
Appendix A .....	6
MJD Foundation.....	6
Machado-Joseph Disease.....	6

## Submission Purpose

The purpose of this submission is to highlight the issues around employment of people living with disability through two perspectives:

- Indigenous people living with disability, especially those living with Machado-Joseph Disease who come from remote and very remote communities, AND
- People living with degenerative neurological conditions.

## About the MJD Foundation

The MJD Foundation (MJDF) works in partnership with Aboriginal<sup>1</sup> Australians, their families and communities living with Machado-Joseph Disease (MJD) in a growing number of remote and very remote communities and urban centres across the Northern Territory (NT) and in Far North Queensland (QLD).

The vast majority of the MJDF's clients live in remote and very remote Aboriginal communities. The MJDF has substantial and unique experience in Aboriginal very remote non-government disability service provision. See Appendix A for further information about MJDF and MJD.

## Employing Aboriginal people with disability

Employing Indigenous people living with disability involves acknowledgement and respect of culturally oriented community issues (closure for respect, gender matching for workforce/clients, family based "collective" decision making), communication in first language (interpreting, different priorities, 'two way' working) and differences in the conceptualisation of disability in western medical terms in an Indigenous context.

Relationships and respect for family and culture are at the heart of successfully employing Indigenous people living with disabilities. The MJDF is only able to do the work it does with its Indigenous clients because it employs Indigenous people and puts the client, family and community needs at the centre of its working culture.

To achieve this client-centred approach the MJDF's engagement model is to always partner non-Indigenous staff with local Indigenous staff called MJDF Aboriginal Community Workers (ACW). This model values and respects a 'two-way' approach. The role of the ACW is to reflect family support needs, facilitate and attend MJDF client home, clinical and other visits with relevant non-Aboriginal MJDF staff; interpret at medical, allied health relevant meetings and appointments; educate and mentor non-Indigenous staff/volunteers about relevant elements of Kinship and Culture; interpret and translate MJDF resources into first language; travel to other communities to talk about MJD and the work of MJDF and plan/attend respite trips as appropriate.

Indigenous Australians comprise 49% of MJDF staff with 18% of MJDF staff living with a disability (mainly MJD).<sup>2</sup> Some of our Aboriginal Community Workers are our clients as well. We aim to

---

<sup>1</sup> The MJDF uses the term Aboriginal in preference to Aboriginal and Torres Strait Islander in recognition that Aboriginal people are the original inhabitants of Arnhem Land. Aboriginal and Torres Strait Islander is referred to in the National context. No disrespect is intended to our Torres Strait Islander families and communities. The MJDF acknowledges the inclusion of Torres Strait Islanders who may be affected by MJD.

<sup>2</sup> MJD Foundation Annual Report 2019-20, p13.

provide them with meaningful employment and opportunities for ongoing education and training.

The MJDF underwent an independent Quality and Safeguards Framework Assessment process for its registration as a service provider under the NDIS in March 2017. That independent assessment found that:

*"clients, their families and their kin willingly engage with the organisation, and make decisions based on cultural and social needs. Family, extended kin networks, and community members are involved in support delivery. Clients interviewed were open, direct, confident and engaging about their experiences with MJD and how the Foundation was helping them and their families."<sup>3</sup>*

This positive feedback from our clients puts MJDF in a good position to recommend ways in which the National Disability Strategy and in particular the National Disability Employment Strategy, should be used to increase the opportunities for employment, and maximise its benefits for Indigenous people with disability in remote Australia.

## **Employing people with degenerative neurological conditions**

For employees with a degenerative or episodic disabling condition, their needs will change as the disease progresses. Such employees will need support throughout their employment pathway, such as retraining as their ability to perform certain tasks changes.

The MJDF employs people living with Machado-Joseph Disease at the mild stage of their disability. As their condition progresses, their symptoms degenerate, and MJDF offers pathways of employment from Aboriginal Community Worker through to: cultural advisor, educator, co-researcher.

Current government programs provide some support to train and mentor people with disability to enter the workforce, but there is little available to support the costs of re-training, and support for an altered employment pathway, to enable employers to support people to stay employed as long as they wish to stay in the workforce. This cost is borne by the employer, and in many cases the focus of the employer becomes supporting the employee with a degenerative disability to exit the workforce.

## **General Comments**

The consultation paper and proposed National Disability Employment Strategy (the Strategy) are silent on measures to improve the employment of Aboriginal people with a disability. The consultation paper states that in 2018 the unemployment rate for people with disability was 10.3%, whereas, in 2015, the unemployment rate for Aboriginal and Torres Strait Islander people with disability was 22.1%.<sup>4</sup>

Similarly, the consultation paper and proposed Strategy make no mention of the impact of remoteness on the employment of people with a disability in remote Australia. The proportion of employed Indigenous Australians declines consistently with increasing remoteness, from 54% in major cities to 31% in very remote areas. The gap in employment between Indigenous and non-

---

<sup>3</sup> Report of MJDF Services Assessed by HDAA to the Northern Territory Quality and Safeguarding Framework, 31 March 2017.

<sup>4</sup> Australian Bureau of Statistics, Disability, Ageing and Carers Australia; Summary of Findings 2015 <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features802015?OpenDocument>

Indigenous Australians aged 15–64 increases with increasing remoteness, from an 18 percentage point gap in major cities to 54 percentage points in very remote areas.<sup>5</sup> Remoteness is a key factor in employment which needs to be taken into account in any strategy to improve unemployment rates.

## Questions for consideration

### ***a) Are there barriers or concerns for jobseekers with disability (jobseekers) not covered in this consultation paper?***

Indigenous employees living with MJD have some characteristics which require different approaches to that of mainstream disability employment, for maintaining their employment: language and disability type (degenerative or episodic condition).

First language support for Indigenous employees living with disability is imperative, especially around training and continued professional development.

For employees with a degenerative or episodic condition, their needs will change as the disease progresses. Such employees will need support in their employment pathway, such as retraining and mentoring as their ability to perform certain tasks changes.

### ***b) Are there barriers or concerns for employers not covered in this consultation paper?***

There is limited or poorly targeted support for remote employers of Indigenous people with disability to adapt the office environment, to access ongoing funding for retraining people, and to provide mentors that are also support workers for training.

For example, 15% of MJDF staff have a disability yet MJDF misses out on funding to put in place practices such as training and mentoring etc to support its employees with disability in the workplace under the Disability Employment Services (DES) program. This is because MJDF does not use a DES provider to recruit staff with disability. MJDF Indigenous staff are recruited from families which are affected by MJD, which allows for appropriate cultural requirements to be respected.

Other programs such as Community Development Program (CDP) are also ineffective for MJDF to use to identify Aboriginal workers with disability. This is because there are cultural requirements to be respected that are not accounted for in CDP.

---

<sup>5</sup> <https://www.aihw.gov.au/reports/australias-welfare/indigenous-employment>

***c) Which actions or initiatives would best create positive change for people with disability and employers?***

The National Disability Insurance Agency should explore how better (and more consistently) it can support participants who have a goal of employment in their plans, and who currently are employed, by providing funding in all such cases.

There are inexplicable inconsistencies in the funding provided between National Disability Insurance Scheme (NDIS) plans for employment goals. Of the 8 Indigenous people with a disability (mainly MJD) employed by MJDF, only 2 of them have funding under the line item “finding and keeping a job” within their plan.<sup>6</sup>

## **Conclusion**

There is insufficient support provided to Indigenous people with disability and their employers in remote Australia. This fact should be reflected in the Strategy, with appropriate solutions proposed and included in the Strategy.

There is inconsistency in funding support for ‘finding and keeping a job’ under the NDIS. The interaction between the Strategy and the NDIS, in particular the support for ‘finding and keeping a job’ should be included in the Strategy.

There is little support for employers to enable them to support employees with a degenerative disability to stay in the workforce.

MJDF is close to finalising its publication ‘MJDF work pathways for Aboriginal staff living with MJD’. A copy can be made available once it is completed.

## **Recommendations**

In order to reflect the experiences of Indigenous people with disability in remote Australia, their employers and those with degenerative diseases, MJDF recommends that the Strategy recognise and respond to the lack of support for:

1. Indigenous employees with disability in remote Australia where English is not their first language;
2. the changing needs of Aboriginal employees with a degenerative disease;
3. employers of Indigenous employees with disability in remote Australia where recruitment is not through DES or CDP;
4. re-training and mentoring support for employers to keep people with a degenerative disability in the workforce if they so choose;
5. ‘finding and keeping a job’ in NDIS plans for some Indigenous participants in remote Australia who are employees.

---

<sup>6</sup> In most cases the staff with a disability employed by MJDF are participants in the NDIS for which MJDF is the Coordinator of Supports.

## Appendix A

### MJD Foundation

Since its inception in 2008, the MJD Foundation (MJDF) has been working in partnership with Aboriginal<sup>7</sup> Australians, their families and communities living with Machado-Joseph Disease (MJD) in a growing number of remote and very remote communities and urban centres across the Northern Territory (NT) and in Far North Queensland (QLD).

The MJDF has substantial and unique experience in Aboriginal very remote non-government disability service provision. Services are delivered in response to the expressed needs of the client base, consistently, despite very high costs. These services were historically frequently designed to fill gaps in government service provision. With the introduction of the National Disability Insurance Scheme (NDIS), the MJDF has increased its supports to further meet some of the supports previously provided by government.

### Machado-Joseph Disease

MJD is a very rare genetic neurodegenerative condition, experienced at the highest rates internationally among Aboriginal people in the NT. It is a terminal condition that gradually destroys independence and impacts on every facet of life.

The disease is extremely disabling, of significant duration - those affected experience progressive symptoms for up to 20 years. Genetic 'anticipation', a phenomenon whereby children of those with the disease experience symptoms earlier than their affected parent means that the age at which the disease manifests is variable, with symptomatic children as young as twelve (12) known to the MJDF. Deterioration of function with MJD is gradual but inexorable and progression is more rapid with earlier age of onset. There is no remission or effective treatments, people who are able to walk independently at the onset of the disease will *always* end up using a wheelchair. Functional change however, occurs gradually over a number of years. During this time care needs change significantly, necessitating regular assessment and good planning.

The vast majority of the MJDF's clients live in very remote Aboriginal communities<sup>8</sup>. Those who live in urban centres such as Darwin, Alice Springs or Cairns have tended to do so in order to access specialist disability or high level support services as their disease progresses.

---

<sup>7</sup> The MJDF uses the term Aboriginal in preference to Aboriginal and Torres Strait Islander in recognition that Aboriginal people are the original inhabitants of Arnhem Land. Aboriginal and Torres Strait Islander is referred to in the National context. No disrespect is intended to our Torres Strait Islander families and communities. The MJDF acknowledges the inclusion of Torres Strait Islanders who may be affected by MJD.

This map shows the locations where the MJDF's clients live and where the MJDF provides services.



<b>Central Australia</b> 1. Papunya 2. Ntaria (Hermannsburg) 3. Mparntwe (Alice Springs) 4. Ltyentye Apurte (Santa Teresa)	<b>Far North Queensland</b> 5. Atherton 6. Kowrowa 7. Ngoonbi (Kuranda) 8. Gimuy (Cairns)	<b>Groote Archipelago</b> 9. Milyakburra 10. Angurugu 11. Umbakumba <b>Darwin</b> 12. Darwin	<b>East Arnhem Land</b> 13. Galiwin'ku (Elcho Island) 14. Birritjimi (Wallaby Beach) 15. Gungyanga (Ski Beach) 16. Nhulunbuy (Gove) 17. Yirrkala 18. Birany Birany	<b>South East Arnhem Land</b> 19. Numbulwar 20. Ngukurr 21. Urapunga <b>West Arnhem Land</b> 22. Gunbalanya (Oenpetli)
--	---	---	--	---